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ABSTRACT

This technical report is part of a series on AIDS/HIV (Acquired Immune Deficiency Syndrome/Human Immunodeficiency Virus) and is intended to help link various legal advocacy organizations providing services to persons with mental illness or developmental disabilities. Such persons, especially adolescents, are at risk for exposure to HIV because they may unknowingly engage in high risk sexual behavior, because they suffer high rates of sexual abuse, and because they may self medicate with drugs. Advocates are encouraged to: consult with AIDS service organizations in creating HIV education programs; conduct a needs assessment of the disability community; design the program taking into account staff and agency needs; and use creative strategies which utilize the press, politicians, service providers, and others. A model program developed by the Michigan Protection Advocacy Service is described, including: goals; objectives; issues surrounding presentations on AIDS/HIV; the training program; the budget; recruitment of trainers and staff; scheduling; evaluation; and education of primary consumers. Listed are 27 references, 22 additional resources, and 12 associations, videos, or manuals. (DB)

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HIV Education for Persons with Mental Disabilities

David C. Harvey, M.S.W.
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Inside Features Include:

Suggestions for Advocates 5
Health Education Policy & Theory 6
Model Programs 7
Additional Resources 13

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National Association of Protection & Advocacy Systems

The National Association of Protection & Advocacy Systems is the membership organization of 86 Protection & Advocacy Systems (P&As) and Client Assistance Programs (CAPs) located in every State and U.S. Territory. P&A agencies for persons with developmental disabilities (PADD) were first created by Congress as part of the Developmental Disabilities Assistance and Bill of Rights Act of 1975 (P.L. 94-103). In 1986, Congress added the Protection & Advocacy System for Mentally Ill Individuals (PAMI) (P.L. 99-319). The Client Assistance Program was created under Section 112 of the Rehabilitation Act of 1973 (P.L. 93-12).

P&As and CAPs are mandated to provide advocacy services through legal, administrative, and other appropriate remedies to protect the rights of persons with disabilities who reside in institutions, facilities, and other locations, and persons being served by state departments of vocational rehabilitation.

P&As and CAPs are increasingly confronting legal, policy and advocacy issues involving adults and infants infected with HIV, and a range of other issues associated with communicable disease policy, sexuality of persons with disabilities, and persons with dual diagnoses of mental illness or developmental disability and drug use. It is the hope of NAPAS that this series of technical reports will assist the field in responding to the newest challenge facing disability services.

Elizabeth J. Bauer, President, NAPAS (1990)
Executive Director, Michigan Protection & Advocacy Service, Inc.

Curtis L.Decker
Executive Director, NAPAS

Purpose of Publication

In 1988, NAPAS submitted a grant proposal to the AIDS Prevention & Service Program of the Robert Wood Johnson Foundation, Princeton, New Jersey, to develop AIDS legal advocacy services through technical assistance to NAPAS members and production of monographs and research articles. NAPAS was awarded a grant January 1, 1989 for one year, together with 54 other grant recipients nationwide.

Published in January 1990, this publication is the first in a series of technical reports on AIDS/HIV legal, policy and advocacy issues pertaining to mental health and developmental services. These technical reports are intended for distribution beyond Protection & Advocacy Systems and Client Assistance Programs to the disability and AIDS community at large, and are designed to help link various legal advocacy organizations in mutually beneficial and cooperative ventures. Although the responses and capabilities of agencies vary throughout the United States, these technical reports may provide assistance to others and can serve as guideposts for other organizations seeking to initiate or enhance similar efforts.

Comments and feedback on the usefulness of this technical report are welcome and should be addressed to David Harvey, Project Director, NAPAS, 220 Eye Street, NE, Suite 150, Washington, D.C. 20002, (202) 546-8202.

This technical report was researched and written by NAPAS staff members David C. Harvey, M.S.W. and Lucy U. Trivelli, Ed.M. David C. Harvey is the Project Director of the Robert Wood Johnson Foundation AIDS grant. The authors wish to thank Carolyn Lejuste and Toni Young of Michigan Protection & Advocacy Service, Inc., Lansing, Michigan (517-487-1755) for their generous time and contributions to this report. The authors also wish to thank the NAPAS AIDS Advisory Committee for assisting with the conception of this paper and review of initial drafts.
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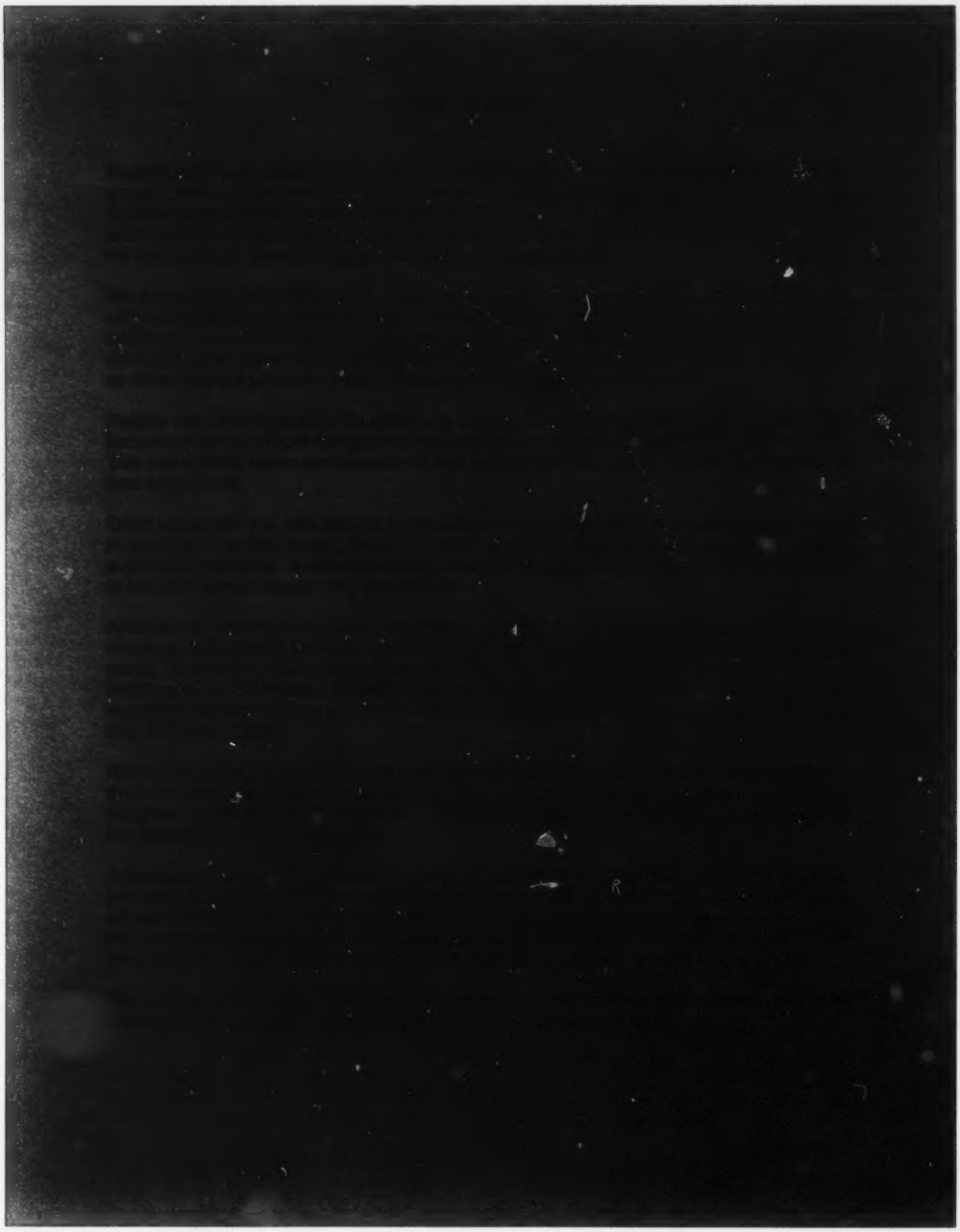

HIV Education for Persons with Mental Disabilities

David C. Harvey, M.S.W.
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Introduction

The Human Immunodeficiency Virus (HIV) which causes Acquired Immune Deficiency Syndrome (AIDS), will increasingly impact developmental disability and mental health services. With the absence of a vaccine to prevent HIV, education is a primary means of preventing the spread of HIV. Primary health education and disease prevention activities should be an integral part of services to persons with mental disabilities in order to prevent transmission of HIV and other communicable diseases. Although not addressed in this paper, secondary education to advise clients already infected with HIV on safe sex, accessing services, and other issues is another priority for disability services.

This paper examines primary HIV education strategies for persons with mental disabilities, and presents a Protection & Advocacy HIV education model that may be helpful for other service providers and community based AIDS service organizations. A goal of this paper is to help disability service providers link resources with AIDS service providers in order to provide urgently needed primary and secondary education for people with mental disabilities.

A complete educational model is beyond the scope of this paper; instead, an introduction to health education theories for persons with mental disabilities with implications for HIV and AIDS is discussed. Strategies are included for advocates and service providers who wish to implement educational programs. Staff must be an integral part of these programs and need to receive advanced training in sexuality, preventive health, HIV diseases, infection control, and other issues.

Epidemiology

A recent study released by the U.S. General Accounting Office (GAO) reviewed existing national forecasts of cumulative AIDS cases and concluded that a "realistic range" of between 300,000 and 485,000 persons with AIDS will be diagnosed by the end of 1991. These figures are higher than what was previously estimated by the U.S. Centers for Disease Control (CDC).

The Centers for Disease Control (1989) reported that in December, 1989, 1,947 infants and children under age 13 were reported as diagnosed with AIDS. It is estimated by the Public Health Service that there will be 3,200 cases of pediatric AIDS by the end of 1991, with at least 10,000 to 20,000 HIV infected children in the U.S. by 1991 (Morgan & Curran, 1986). Further, it is estimated that in the next five years, HIV may become the largest infectious cause of mental retardation and encephalopathy in children under age thirteen (Diamond & Cohen, 1987).

There are currently no prevalence studies of HIV among persons with disabilities. Harvey and Elliott (in press 1990), found that of 85 state and county mental hospitals across the country responding to a twenty item questionnaire, most report some in-patients with HIV infection. Staff reported that these patients raise difficult patient management issues, and that the CDC guidelines on prevention of HIV in hospitals does not address the circumstances of sexual and violent behavior that can happen in state mental facilities. Other studies describe the provision of services to adults with mental retardation who acquired HIV (Kastner, Hickman & Beelenhumeur, 1989).

A recent study by Marchetti, Nathanson & Kastner (1990) found state developmental disability agencies reporting that AIDS policies adopted by states varied considerably. Only 10 out of 44 States responding to the study conducted AIDS prevention activities for their clients, with such training more likely to be provided in institutions. Eleven states reported persons with developmental disabilities who acquired HIV infection, and several states reported some form of segregation of these individuals. Twenty five States responded that information on AIDS is provided in staff training curriculum, with such training more likely given to institutional staff than community agency staff.

HIV Diseases

Knowledge of the clinical course of HIV infection has developed rapidly in the last few years. The Centers for Disease Control developed initial definitions of AIDS in 1982 and then revised the criteria for diagnosis in 1985 and 1987 (MMWR 35, 1986; MMWR 36, 1987). A diagnosis of AIDS includes the presence of opportunistic infections and malignancies. In 1987, dementia and wasting syndrome were included in the criteria for diagnosis. Many persons with HIV experience clinical symptoms and abnormalities that indicate the presence of disease but do not meet the CDC definition of AIDS or AIDS Related Complex (National Academy of Sciences, 1988).

Of specific urgency for mental health and developmental service providers are symptoms of HIV infection of the brain which can include regressed behavior, apathy, social withdrawal, depressed mood, and some organic psychosis. As HIV brain diseases progress, the person with AIDS may have moderate or severe dementia that can include psychomotor retardation, total persistent organic psychosis, and severe motor weaknesses (Bridge, 1989; Rubinow, et al., 1989). Central nervous system (CNS) dysfunction in infants and children with symptomatic HIV infection ranges from 78% to 90% in various studies. The presence of HIV in CNS may produce progressive encephalopathy, experienced by loss of developmental milestones, intellectual deficits, impaired brain growth, other symptoms and death (Diamond & Cohen, 1989).

Psychiatric research and literature journals have begun to deal in depth with mental illness caused by HIV, as well as presentations of HIV in state mental facilities (Horwath, 1989). Mental health services will be increasingly challenged to distinguish the cause of mental illness as resulting from HIV infection or organic syndromes.

HIV Transmission

Blood, semen, breast milk, and vaginal secretions have been implicated in HIV transmission. Studies show that HIV transmission can occur only through significant exposure to infected blood (through transfusion of contaminated blood or blood products, use of contaminated needles or syringes in IV drug use, needlestick injuries), sexual contact (unprotected anal or vaginal intercourse where blood or semen is exchanged), perinatal transmission, and transplanted tissue or organs from an infected donor (Friedland & Klein, 1987).

Concern has been expressed by developmental and mental health services in situations involving bites. There are no documented cases of HIV transmission through bites. Studies have shown that biting is not an efficient means of transmission of HIV (MMWR, June 23, 1989; Rogers, et al., 1990) although, theoretically, if blood is present in the mouth of the one biting, and a tear in the skin occurs on the victim, HIV transmission could occur. However, risk of transmission through this means is most likely remote.

Future Policy Issues

Issues involving HIV for providers of developmental and mental health services are profound. Increasingly, residential, habilitative, rehabilitative, child welfare and social services, health care and educational services designed to treat and care for persons with developmental disabilities will be forced to confront a new group of developmental disorders caused by infection with HIV. Persons entering developmental services with HIV, or the later stages of infection that results in a diagnosis of AIDS, will be of all ages that include infants who mature with developmental delay, to the adolescent or adult with developmental disability who acquires HIV through high-risk sexual activity or IV drug use.

Mental health services will be increasingly impacted by the adolescent or adult with chronic or severe mental illness who at times may have impaired judgement and because of possible accompanying high-risk behavior, may be at increased risk for HIV transmission. Mental health services include large state facilities, community mental health centers, rehabilitative and vocational day programs, and community residential services. Little is known about the etiological consequences of HIV infection in persons already diagnosed with mental illness, or about the interaction of drugs used to treat HIV and psychotropic medications.

Concerns about HIV have highlighted existing issues involving infection control procedures and whether disability services adequately implement them, sexual behavior within facilities, confidentiality and duty to protect, placement of clients in community settings and the least restrictive environment, and management of the non-compliant or recalcitrant client. New issues regarding the Centers for Disease Control's (MMWR, June 16, 1989) call for early HIV testing and access to treatment may have particular ramifications for persons with disabilities under state guardianship.

Advocates are defined as any person, whether through volunteer, lay or professional means, who addresses the needs of other persons in need or assists persons who are not empowered to speak for themselves. This broad definition of advocate crosses most professions and human services, and is used here to identify volunteers and staff who may work for AIDS service organizations, professional social workers or attorneys who may work for Protection & Advocacy Systems, and many other service providers and policy-makers who are in positions to influence the delivery of health services.

Advocates for people with mental disabilities are of special concern here because they speak for a population that is one of the least empowered to speak for themselves. These advocates must be called upon to address the urgent issues of health maintenance and disease prevention, with specific concerns around HIV and AIDS.

In designing and advocating for creation of health education programs for persons with mental disabilities, the following activities should be conducted by advocates, some of which are adapted here from a publication by Elizabeth Randall-David, Ph.D. (1989).

- Conduct a Community Assessment
- Develop Relationships with Key Persons in the Disability Community
- Consult the Literature
- Secure Funding Mechanisms
- Market Services to Community Groups and Targeted Populations

Advocates dealing with HIV issues should participate in the disability community by attending meetings, observing participants, and learning the cultural values of various groups and persons of minority status. The advocate needs to expose him or herself to as many different viewpoints as possible by meeting with consumers, parents, advocates, legislators and activists.

Second, all disability institutions and agencies that might benefit from health education programs should be listed. Include a list of key supports such as funding institutions, businesses, or state departmental agencies. Also include a list of targeted leaders such as administrators, directors, consumer leaders, politicians, etc.

Finally, conduct in-depth interviews with organizations and persons, conduct research on available literature and case studies. Determine areas where more information is needed. Persons may be distrustful of intentions and may need the advocate to prove him or herself. Cultural barriers may also exist and myths will need to be confronted around a range of issues involving sexuality, IV drug use, and people with disabilities.

Advocates should also consider the following factors in establishing primary health prevention and HIV education programs:

1. The audience must be assessed by age, culture, educational level, cognitive and emotional development, and diagnosis.

2. Staff must be an integral part of educational programs and should receive ongoing, advanced educational programs on HIV, disease prevention issues, sexuality, and other issues. Staff must be educated before clients.

3. Agency or institutional policy must be considered in educational programs while maintaining the integrity of HIV prevention efforts.

4. Advocacy efforts to initiate health education programs may require creative strategies. Advocates may need to draft proposals, contact state officials, appeal to facility directors, mobilize consumers and families, conduct investigations, write press articles, in addition to other strategies. Advocates will need to confront myths and common misperceptions about sexuality and people with disabilities, policies regarding sexual behavior in institutions and community agencies, and the fears of staff, parents, and politicians.

5. AIDS and health education experts should be consulted in creating and implementing programs. AIDS Service Organizations and Community Based AIDS Organizations can provide valuable expertise. Where possible, strategies and services should be linked between agencies and service providers.

Historically, discussions about sex and sexuality among persons with developmental disabilities or mental illness have been taboo subjects and rarely discussed in public forums or with clients. During the past 15 years, a shift in public attitude has allowed some increased attention to these issues. Recent studies have focused on client, parental and institutional attitudes, sterilization issues, and sex education largely in the developmental disability community (Murphy, Coleman & Abel, 1980). There are fewer studies dealing with sexuality of persons with chronic mental illness. These issues now have new urgency because of considerations about HIV and AIDS.

Often overlooked in forming disability policy is the right of persons with mental disabilities to sexual expression. Gebhard (1973) and Mulhern (1975) demonstrated that problems concerning sexuality and persons with mental disabilities have more to do with the attitudes of staff and care-givers, rather than clients themselves. Coleman & Murphy (1980) found myths, misinformation, and incorrect beliefs have persisted in institutional settings. These myths include beliefs that persons with mental disabilities are oversexed, undersexed, lack control, have diminished cognitive capacity to understand sexual behavior, are unable to make informed decisions regarding sexual partners, are unable to use contraceptives, and are unable to be parents.

Coleman & Murphy (1980) further found that the competing interests of schools, administrators, parents, staff, community leaders, and advocates may be in conflict with the rights of the individual with a mental disability to sexual expression. Residential, day programs, developmental centers and schools are primarily community based and therefore, reflect local culture and mores of society. Accordingly, similar issues regarding sexual behavior of persons with mental disabilities resemble institutional beliefs. American society has often handled sexuality education among the general population in a contradictory manner.

Clearly, when sex education policy is viewed from a societal perspective, it is understandable that persons with mental disabilities are poorly educated on sexuality. This accounts for the lack of consensus on sex education and sexuality, and the absence of guidelines for the provision of education on HIV prevention.

Coleman & Murphy (1980) also found that even when sex education is provided in institutions, very few actually allow sexual expression (except for masturbation) or provide privacy for such activity. This study also found that the penalty or threat of punishment for engaging in sexual activity is often severe enough to discourage residents from doing so. Expulsion from a residence is not uncommon; hence, what is overtly sanctioned or permitted is covertly discouraged through penalties, lack of privacy, staff values, or other factors.

The Accreditation Council on Services for People with Developmental Disabilities (ACDD), a national professional, advocacy and quality assurance organization, has recognized the rights of individuals with mental disabilities to sexual expression. Sexual rights statements are included in a 1990 standards statement: "citizens with developmental disabilities have the same rights as other citizens. Some of these rights are: the right to express sexuality, and the right to marry and have children" (ACDD, 1989).

Hall and Sawyer (1978) found while examining facilities for persons with mental retardation in the Southeastern U.S., those attempting to develop sexual expression policies accepted the basic assumption that individuals with mental retardation have a right to express their sexuality and to develop appropriate sexual behaviors within their capabilities. The study found consensus that sex education and family life planning programs must be available to all persons with mental retardation if healthy social-sexual expression is to be achieved. The study also found that homosexuality is only addressed in one policy, which stated that while it was not encouraged, it was recognized as one form of sexual expression that is acceptable to some as long as it is between consenting individuals and in private. In most States, homosexual acts are defined as criminal behavior and therefore not permitted in institutions. Kirby (1988) emphasizes that if AIDS education is to be effective, it must be integrated into a comprehensive, community-wide program that reinforces what is learned. AIDS education should teach more than facts, it should teach skills and increase motivation to avoid high-risk behavior, which is a special challenge for persons educating people with disabilities. In addition, these programs must be sensitive to the values of cultural minority populations.

Education Models

Health education models predominantly subscribe to three schools of thought: factually based presentations; behavioral approaches; and school or institution based programs. Factually based presentations avoid discussion about morals, and provide basic medical and technical information geared towards the cognitive and emotional level of clients. This "straight talk" approach does not include education on relationships skills or behaviors. For example, the Young Adult Institute, Inc. in New York City, has produced an explicit video on the specific mechanics of preventing HIV transmission. This video has been used in conjunction with other training programs that include relationship skills or behavior change.

The behavioral model aims to teach preventive behaviors, assertiveness, reasoning and decision-making skills. These types of programs are more comprehensive in nature, are often integrated into a curriculum, and include other topics of health, sex education and sexuality. One example of this approach is the "Circles" model which teaches relationship and sexuality skills by using visual circle graphics to help clients learn who is appropriate for handshakes, hugs, kisses, and so forth (Champagne, et al., 1982).

The school based models usually center on the health course curriculum unit on communicable diseases. Because health educators are trained in methods to help students make disease prevention decisions, the health course can be an appropriate place to deliver educational programs on HIV.

Specifically for the young adult receiving special education services, however, school based education may not universally hold true. Depending upon the type or level of special education services directed by the student's Individual Education Plan (IEPs), and if these topics are included in the school's regular and/or special education curriculums, the youth may or may not have access to this information. In addition, the information may not be provided at an appropriate level for the youth.

An institutional based model attempts to involve staff early in the process to help identify client or patient characteristics, needs, and scope of the educational program. Needs assessments and discussions with the staff are really the beginning of patient education programs (Houston-Hamilton, Day & Purnell, 1989).

The institutional model as outlined by Houston-Hamilton, Day & Purnell (1989) further defines a program that avoids emotional disruptions; provides unambiguous, simple and direct information; overcomes difficulties of medication side effects; is scheduled during a time when patients and clients can be available and attentive; delivers consistent messages; and accounts for magical thinking of some clients or patients. In mental hospitals, some patients may be well educated and can integrate sophisticated educational messages well. In other facilities, clients with developmental disabilities may have cognitive or perceptual disabilities and programs will need to be tailored to appropriate levels.

The central goal of all AIDS education programs is to teach individuals with mental disabilities to establish realistic and sound attitudes about sexual relationships and personal activities, and how to maintain a responsible sexual lifestyle that protects health and well-being.

Several models for HIV education of staff and clients exist throughout the United States. Outlined below is a program provided by Michigan Protection & Advocacy Service, Inc., which provides HIV education programs in "train the trainer" format for mental health professionals while also providing information on self-help groups. In addition to this model, Michigan P&A also has provided some educational programs directly to clients. Other programs can be consulted for more direct experience with education of primary and secondary consumers.

Michigan Protection & Advocacy Service, Inc.

Michigan Protection & Advocacy Service, Inc., has nine regional offices throughout Michigan with a lead office in Lansing. The agency is a private, non-profit and tax exempt charitable organization established for the purpose of: (1) providing rights protection and advocacy services to persons with developmental disabilities and persons labeled mental ill; and (2) providing training and education to persons with developmental disabilities, service providers, parents, guardians, and the general public with respect to rights of persons with developmental disabilities or persons labeled mentally ill.

The agency is independent of any other agency which provides services to persons with developmental disabilities or persons labeled mentally ill. There are no charges for services provided to clients. The agency is funded by federal and state authorizations subject to legislative appropriations. The agency has special grant-funded projects that include the Michigan Self-Help Clearinghouse which conducts AIDS/HIV education programs.

In addition, Michigan P&A has a department and team of staff that do publications that explain civil rights and promote the philosophy of normalization.

Michigan Self-Help Clearinghouse & Michigan State University AIDS Education Project

The Clearinghouse based at Michigan P&A is a statewide resource center for self-help/mutual support groups. As a prevention program funded by the Michigan Department of Mental Health, the Clearinghouse promotes the development of supportive connections between people with similar concerns, including HIV issues.

The Michigan State University AIDS Education Project is a statewide program housed in the Colleges of Human and Osteopathic Medicine and funded by the National Institute of Mental Health. It provides training about the psychosocial, mental health, and neuropsychiatric aspects of HIV infection to health care professionals and students in the fields of medicine, psychiatry, social work, psychology, and counseling. Composed of community and professional curriculum components, the AIDS Education Project is staffed by experts in psychiatry, medicine, ethics, psychology, education, evaluation, and sociology.

The Michigan Department of Mental Health offered the Clearinghouse and the Michigan State University AIDS Education Project a partnership opportunity to provide training about AIDS and HIV infection to service providers and consumers in Michigan, with a particular goal of reaching low-incidence areas to maximize preventive efforts.

Goals

Major goals of these grant activities include the following:

1. Become acquainted with how individuals experience and adapt to AIDS as a chronic illness.
2. Become familiar with existing social service resources available to people with HIV infection.
3. Identify relevant approaches to the provision of counseling and support services to seropositive individuals.
4. Understand the local and federal laws related to HIV infection in the State of Michigan.
5. Learn methods of community organizing and their application to HIV infection and AIDS.
6. Understand and encourage the development of the self-help model in local communities.

Objectives

The first objective of the HIV education program is to prepare community mental health staff and developmental service providers on community organizing strategies to assist people affected by HIV infection. Through learning existing service systems and resources, strategies are discussed for developing and linking service systems. A second objective is to help human service staff identify personal concerns in working with people who have HIV infection and strategies for avoiding burnout. A parallel is drawn between working with people who have other disabilities to that of HIV infection as an increasing long-term, chronic disability.

Finally, basic information on state and federal laws and regulations protecting persons with HIV infection is

provided to participants. Through this program, an adapted "train the trainer" model has been implemented and is targeted to professionals and care-givers so they may instruct other co-workers on HIV issues and better confront day-to-day issues in the workplace.

Issues Surrounding Presentations

The major issues surrounding presentations on AIDS/HIV included the following:

1. Determining sensitivity and knowledge level of participants and developing awareness of how community organizing skills, knowledge of the law, psychosocial and counseling issues, and knowledge of self-help groups can be utilized.

2. Identifying and confronting personal attitudes and beliefs, and understand "deviance from ideal norm" and feelings of isolation, anger, guilt and self blame that mutual support may alleviate.

3. Transfer information and social support into action and behavior change on behalf of caregivers and clients.

Recruitment and education through informal means and telephone contact served to help publicize the workshops, as well as dissemination of a brochure. Input was invited by organizers and participants in workshop presentations, and networking to establish contact with existing organizations also helped to promote the program.

Training Program

The six-hour program on each of two separate days, includes a brief overview of medical and etiological aspects of HIV. This is followed by a discussion of available social services in the community, community organizing skills among service providers and consumers to link and create additional resources. A discussion of HIV legal issues among persons with HIV and implications for service providers is included.

In the afternoon on one day, the discussion centers on psychosocial issues and counseling strategies. A small group exercise challenged participants attitudes for those perceived as "different", and examined personal values and beliefs concerning homosexuality, IV drug use, age, race, sex, behaviors, and persons with disabilities. A "fallout" shelter exercise developed by Dr. Mary McCormack, a faculty member at Michigan State University, is conducted where the goal was to reach a group consensus about which individuals at various stages of HIV infection would be allowed in a shelter in the event of nuclear war.

A second exercise examined a case study of a person with HIV seeking counseling and assistance. Participants discussed their reactions to feelings about clients with HIV in the clinical and social service setting. During lunch, time was provided for an optional activity to watch videos of people with AIDS telling their personal stories. Different videos were chosen according to the culture of the specific training area: a video where gay male couples spoke out; a video of a woman from a Native American tribe who was a former IV drug user; a video which targeted adolescents. The afternoon concludes with a discussion of self-help for caregivers, both lay and professional, and shares ideas about professionals interacting with self-help groups. A video is shown which portrays the impact of AIDS on professional caregivers and family members.

More specifically, the basic content of workshops included the following issues:

1. Overview of HIV, immune system and clinical course of disease, and transmission factors.

2. Specific social service agencies serving people with HIV in medical, social and legal needs.

3. Community organizing skills to network services, link resources, strategize for new service delivery, and mobilize consumer advocacy.

4. Legal issues overview of major federal and state fair housing laws, liability concerns, anti-discrimination remedies, and confidentiality, and legal advocacy service needs of persons with HIV.

5. Psychosocial issues and counseling strategies for clients with pre-existing disabilities.

6. Cultural aspects of sexuality, values and beliefs.

7. Homosexuality and IV drug use.

8. Psycho-social aspects of HIV and AIDS.

9. Sexually transmitted diseases and preventive health concerns.

10. Death & dying, grief and loss.

11. Self-help support groups and avoidance of staff burnout

The Budget- FY '89-'90

As follows, the budget for the Clearinghouse and MSU project highlights how resources are spent to provide such education workshops.

$14,000	Personnel (.75 FTE)
	10 hours per week of P&A staff
	10 hours per week of Clearinghouse Director
	10 hours per week of clerical support
$6,200	Fringe Benefits
$2,500	Travel
$1,500	Supplies
$2,600	Contract Services/Panelists
	$60 honoraria for each panelist
$1,800	Communication/Postage
$1,000	Rent/Space
$2,000	Printing
$3,700	Logistics
$35,300	Total Budget

Overall, the agency planned the cost for each training to be $1,200, or $60 per person. The agency charged a registration fee of $20 per person to help defray logistical costs.

Recruitment of Trainers & Staff

Michigan P&A utilized existing expertise of staff on disability, legal, policy and advocacy issues and most importantly, consulted with other AIDS service organizations for specific expertise on HIV related issues. In addition, existing staff expertise was utilized in special education issues, sexuality and persons with disabilities, normalization, infection control policies in facilities, and other issues of concern.

The Michigan State University faculty assigned to the project provided specific expertise on etiological and medical aspects of HIV, and the neuro-psychiatric manifestations of HIV infection. The research based faculty have access to the latest developments in bio-medical issues of HIV.

Other guest presenters for the workshops were invited from local community-based AIDS organizations and volunteer service organizations serving the State of Michigan.

Scheduling

Program staff schedule during the days depending on service providers' schedules, are scheduled regionally. Registration is required in advance with payment. Events are usually scheduled in rooms that are free to the public, such as local libraries. Utilizing these free spaces means that scheduling needs to happen weeks or months before the event. Advertising for the event through brochures is conducted and multiple copies are mailed to various Directors of programs for distribution. Program staff have a computerized system for registering participants upon receipt of the registration form.

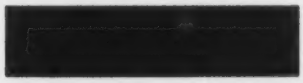
Evaluation

Michigan P&A Service has a general evaluation form for education and training programs. Michigan State University has adopted a specific pre and post evaluation format that seeks specific information from participants on attitudes and knowledge of HIV diseases, minority issues, counseling strategies, sexuality, and other issues.

Education of Primary Consumers

Michigan Protection & Advocacy Service, under its Publications and Training Department, also conducts consumer education programs which involve more explicit education about disease prevention and safe sex practices directly with clients. Staff who are knowledgeable about special education issues and techniques for instructing persons with mental disabilities are utilized. As a separate program from the Clearinghouse and Michigan State University project mentioned above, this education project is funded separately as part of other ongoing training and publication projects.

The consumer education program utilizes the AIDS education video produced by the Young Adult Institute in New York City, and also incorporates a behavioral model which seeks to examine relationship and negotiating skills geared to the emotional and cognitive level of clients.



HIV disease and AIDS threaten the American health care system perhaps like no other modern disease. As society attempts to grapple with the profound crisis in health care financing, health insurance, access to services, anti-discrimination measures, and a host of other issues, AIDS may prompt wide-ranging reforms.

The fields of developmental disabilities and mental health must be prepared to cope with this new disease and the ramifications for existing services and financing mechanisms. If the field does not respond adequately to this new challenge, an opportunity may be lost to not only improve and redress existing inadequacies, but a range of persons will not receive the services and benefits that should be provided by an affluent society.

Education is the only means now available to prevent transmission of HIV. Staff and other care providers in developmental and mental health services must link and combine resources with AIDS service organizations in order to provide preventive health education programs to save lives.

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Associations, Videos, Manuals

American Association of Sex Educators, Counselors & Therapists (AASECT): 5010 Wisconsin Ave., N.W. Suite 304, Washington, DC 20016.

Phi Delta Kappa, P.O. Box 789, Bloomington, IN 47402-0789

The Association for the Advancement of Health Education (AAHE), an association of the American Alliance for Health, Physical Education, Recreation and Dance (AAHPHERD), 1900 Association Drive, Reston, VA 22091.

Council for Exceptional Children: Washington, DC; Association for Advancement of Health Education: Alexandria, VA. Contact Ms. Ginger Katz (703-264-9451).

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Psychosocial Interventions in AIDS Video. Carle Medical Communications, 110 West Main Street, Urbana, IL 61801 (217) 384-4834.

InfoYouth AIDS Prevention Interactive Videodisc for Adults with Mental Retardation." Available from InfoYouth, 1995 University Ave., Suite 215, Berkeley, CA 94704, (415) 644-9901. Contact Lewis Kraus or Alice Rose.

AIDS: Training People with Disabilities to Better Protect Themselves; Video & Manual. Young Adult Institute, 460 West 34th Street, New York, NY 10001

All Involved Deserve Support Video. State of California Health and Welfare Agency, Department of Mental Health, Office of Prevention, 2340 Irving Street, Suite 108 (415) 557-3470.

NAPAS *National Association of Protection & Advocacy Systems*

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